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Session 8
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Where And How do People Want to Live

1. Introduction

In this afternoon's theme "Where and how do people want to live", all words are in fact important points of reflection.

○ **People:** tells us that we are dealing with people like you and me, and yet they are different, as they are moderately and severely mentally handicapped adult women.

○ **Where and how:** should render how things are going, which physical and psychical space is allotted to them.

○ **To live:** indicates that we are dealing with the whole existence of these people, their residing, their working, their being alone, their being together.

○ **To want:** might be the most important concept of all, for "to want" and "to wish" express a choice. And that is what it is all about this week, isn't it? If you say "to want" or "choices", that means that those people find themselves in a situation in which a choice is possible. It is these situations, with their possibilities and limitations that we would like to look into at present.

The whole social context and how we function in it as individuals 263

and as a group is a defining factor for the choices we make. For our mentally handicapped women, this is as much the case as for anyone else.

As an example I would like to mention a few points of general social historical interest that were (and are) of fundamental importance to understand the concrete situation of those thirty women who now live in the Molendreef at Lovendegem in Belgium. Over the last ten years some changes have occurred in thought and action concerning those people.

1. 1. In the first place we must understand that with the appearance of lay-workers (i.e. people who have not taken holy orders) in the daily work with children and adults, our disabled fellow-man has also come in touch with a world different from the one within the walls of the institution.

Several adults were taken in by the institute when they were children. They have grown up there and have mainly learnt to know the life of the Roman Catholic Sisters who were looking after them (Sisters of Charity).

The contact with the laity now also gives them other points of comparison: family, excursions, getting married or not, having a job, going to the hairdresser's, fashionable clothes, etc. Furthermore there has been a tendency towards a growing frankness concerning community life. People started to talk about normalisation and integration.

Calling in the help of lay-staff was also the result of a changed legislation in the matter: a greater number of staff could be put to work so that more educators were responsible for fewer people. There was also an increase of trained staff.

1. 2. A second train of thought which had a great impact was bringing together handicapped people in so-called living units. About ten people live together attended on by a team of educators, in circumstances that rather appeal to an independent attitude, social competence, social intercourse, a homely life, in brief, a more normal way of life resembling the way of life of the average citizen.

This life style obviously differed from what the women had known as children or adolescents. Formerly, some had had a relatively independent and individual life as auxiliary staff with a great amount of manual work and the supervision of younger mentally handicapped people.

Others were used to living together in great numbers in wards; still others had been staying at home for years and had been taken in by psychiatric institutions, which again means immense groups. The idea of gathering mentally handicapped people in living units fitted in perfectly well with the previous tendency: a larger staff.

1. 3. During approximately the same period a third phenomenon occurred: namely the insight that the handicapped, once they turn to be adults form a specific group with its own expectations and questions, different from those that children have. This meant that our grown-up women should get their own provisions, but also some attendance which both in spirit and in deed, could provide an answer to their own specific questions.

Both the idea of living units and the idea that they grew up the way other people did, quite soon got the support of the subsidizing authorities and also received great acclaim from the institutions. This remarkable coincidence of some new views during approximately the same period, together with an almost immediate response of legislation on this point, have caused a turning point in the service to mentally handicapped people.

Thirty women live in a world with the characteristics we have just summed up. It is about these women we want to tell you a few things. Their concrete lives, their options are mainly defined by our thoughts and actions. This is a first relativity as to their opportunity to "choose".

2. The house and its "candidate-residents"

We would like to proceed with a more concrete introduction of the ladies on whose behalf we speak in this report, as well as of the home.

2. 1. About three years ago three houses were built. In each home ten women, i.e. a relatively small unit, could live. Each home has its own living-room, including sitting-room and dining-room, a terrace, a kitchen, storage space, front and back door, bedrooms (single, twins and three-bedded), baths, toilets etc. The three houses stand in a row among the other houses along the village street.

However, there is extra space for a private lawn, a little garden and a few sheds for domestic pets. Although only a rather busy street separates the houses from the rest of the institutions, they are felt, both by the residents and by ourselves, as a relatively independent entity. This fact constituted an important change in the life-style and the concept of life of the residents.

Most of the residents came from our own institution, or had been staying in our institution for some time in the past. A few among them had acquired a certain status as auxiliary staff, while the rest of them had always belonged to the big group in which they had been treated and entertained in the best possible way.

A few other candidate-residents came from psychiatric institutions. In other words, the personal background, the case-history was quite different. This also meant that they had had a different setting of learning and experience, which would undoubtedly play a part after forming new living units.

The average age in each house is respectively 38, 33 and 40. The average I.Q. ranges from 30 to 40 (Terman). The average social age, measured by the Vineland Social Comp. Scale is between 8 and 11. The general level of functioning is, if we may globalize, severely to moderately mentally handicapped.

Each living unit is directly attended on by three educatresses. Indirectly the whole staff of the service centre, s.a. pedagogical team, therapists, social workers are involved. The adults who were already staying at the institution and who qualified for the homes, didn't actually live in a community until approximately 1974. During the daytime they assisted the educatresses and at night they went to their bedrooms in various parts of the institution. At mealtimes however, they used to go to the same room, which functioned as a sitting-room and dining-room.

They all went their own way, though; the first to arrive was the first to eat, etc. There was also a certain mutual hierarchy, through which the mutual problems were solved.

Their work, in fact, was hardly attended on at all, which was, of course highly questionable as for the relationship with the children they were responsible for: some of them got attached to some children too much, other children were rejected, personal problems were worked off on them etc. Their leisure was restricted and was spent monotonously: watching the telly, walking about, doing some needlework, listening to the radio. It was clear that moving to the houses would thoroughly change their way of life.

2.3. All these changes could of course not take place straight away; for there was not only a change in material surroundings, but there was an appeal to their flexibility, their adaptability as well.

The actual removal was first preceded by a period in which the women got used to living together and also by a diagnostic examination shortly before the removal.

Getting the candidate-residents used to living together was achieved as follows. They were asked to have their meals together and to spend their spare time in the same room. There they were received by an educatress.

Gradually they came to form a group and they came to do more things together: upkeep of their common room, entertainment. In this way an evolution took place from a separate individual life towards a community life, which was furthermore attended on by an educatress, i.e. someone who was younger than they were, someone who was not invested with the evident authority of the sister. This was something they would formerly have rejected as a meddlesome form of curiosity.

The diagnostic work consisted of determining the women's I.Q.s and their social competence. Furthermore an attempt was made to compose a sociogram, in order to recognize mutual likes and dislikes, concerning the questions who to share one's spare time with, who to do the chores with, who to share a bedroom with, who to go on holiday with. This took place by means of a number of concrete questions to which they could give positive or negative answers.

To support the selection the interviewees were shown pictures of the various candidates. This means that in the selection not only the results of the tests were taken into account, but also the personal preferences of the women themselves. Also the personalities of the adults, as one had got to know them throughout the years, were taken into account. Although it would be an obvious inclination not to let people with character difficulties take part in the removal, they were given a chance anyway, hoping that the change of life style could cause a positive development for them. After the event we must admit that most of them have taken this opportunity to their advantage. They succeed in holding their own in a more sociable way and the group can manage to live with them, although not without difficulties.

Of course, we could wonder in which community, consisting of ten adults, living together day by day, no moments of tension occur.

3. A new life style . . . new opportunities

Now that we know who took part in the removal and what it was

preceded by, we would like to draw the attention to the actual changes in life style and to the residents' reactions. At the same time this provides us with a picture of how things are going at present.

To make things more surveyable we distinguish between the following themes: residence, work, leisure, personal development, always keeping the question at the back of our minds: "What about choices?"

3. 1. A first serious change was the question of residence. The rather solitary life in a big ward was turned into a community life in which the individuals developed closer relationships. Furthermore, a change of mentality, namely convincing them that there was more to life than just work, had to be effected.

A number of skills could be put into practice in the new residence: learning how to make coffee, lay the table, clear the table, do some minor washing, and parallel to all these to consider other people, and not only themselves. They were also able now to cook in their own kitchen. To this effect, the candidate-residents had attended a series of cooking lessons. What they had learnt there could be put into practice under the guidance of an educatress during the weekend or on special occasions such as a cooking contest. These cooking lessons are organised every year, so that more and more adults acquire this skill.

At present, dinner is cooked by the residents themselves on Saturdays and Sundays. Beforehand they discuss with the educatress what they will cook and how to prepare it. Especially the dessert gives them ample opportunity to develop their own creativity and personal taste. On the other days, they still get food from the central kitchen.

In choosing the food and composing the menu, e.g. we have found out that attendance remains indispensable so as not to come to extreme situations in which everybody wants his own menu, or menus that are too expensive because they have not reckoned with cost price, seasonal vegetables or fruit.

Residence also includes furnishing, decorating and keeping the premises in repair. A few adults used to have their own room, which was frequently badly kept. Others had always had a bed in the spacious dormitories and were consequently not used to keeping a wardrobe or washbasin tidy.

At the house they have single, twin-bedded or three-bedded rooms. Attended on by the educatress they can choose their own

wallpaper, which picture or poster they want, what colour the furniture should be. They can make a lot of objects s.a. cushions, bouquets, tapestries themselves. Interior decoration is at the same time a motivation for keeping them at work in their spare time.

Keeping plants, a vegetable garden or a few domestic pets, are other examples of new opportunities. As more attention was paid to residing in itself and to residing in a community, an opportunity to enjoy this home was created. Many of them are very proud of their own room, where they have their personal belongings, s.a. photograph albums, souvenirs, letters, New Year's presents.

This style of life, which provides the chance to take care of an own home, to enjoy a home-made cake, fireside comforts, more and more came to resemble the life style of any adult, s.a. their educatresses', their families', but also their neighbours'.

If we look at the residential aspect from the outside, we notice that their terrace houses are situated along the village street, only a short walk from a newsagent's, a greengrocer's, a printer's. Across the street there is an ordinary elementary school; the new communal multi-sport gymnasium is only two blocks away, etc. This means that they live in the centre of the community, just like the family on their left and the family on their right. Once again new possibilities, new opportunities for choice. But again a choice that is attended on. Not only because they are handicapped, but also because the community has remained handicapped in living together with mentally handicapped people.

By the way, may we point out again that integration is a double-edged sword: not only our handicapped women have to learn how to cope with social intercourse, but every citizen must learn that integration means more than tolerance, it includes letting people know and feel that they are part of it.

Though the village, and more particularly its inhabitants, used to be unknown territory, Lovendegem now became a place to explore. Not only do they make use of the same post office, parish church, gymnasium, swimming pool, etc. There is also an increasing personal contact with the people themselves. About ten women are members of an adult organisation, and they got acquainted with people who came to mean something to them. Also independent initiatives such as "sport for women", cooking courses, sewing and knitting courses are sources of new choices: "Shall I go?", "Could I manage?", "Who shall I associate with?" etc.

We can evidently see a positive evolution: amazement and disappointment, and once in a while some negative criticism about the fact that mentally handicapped people came to live in the immediate neighbourhood. From all this we have evolved towards a situation in which our people are no longer strangers. Some of them have even succeeded in building up real friendly relationships.

It is quite obvious that in the beginning there were a few disagreements, for suddenly getting an extra thirty neighbours is not an everyday phenomenon. Furthermore, these neighbours and the whole community had always been outsiders in the most literal sense of the word. Until the moment of the concrete realisation (building and removing), they had not taken part in the change of mentality, the growth of which had gradually taken place among the insiders. A few talks and an invitation to visit the new homes could not be more than the start of an important change in their thought and action; a change that is still going on, by the way.

3. 2. More time and attention could be paid to living together due to a reorganisation of their working situation. In the morning they go to work from 8 to 12. Some work as charwomen in a living unit consisting of children. Others work as auxiliary staff to the kitchen or to the seamstress. From 2 to 5 in the afternoon they go to a workshop where they have a choice to learn a great variety of manual jobs. On weekends and on Bank holidays, they have the day off. This has resulted in an equality among all adults, in spite of the differences in their level of functioning. Doing a similar job, or at least a job that is appreciated in a similar way, to them constitutes a proof of equality and competence. This is something that a few among them had, and still have, difficulties in coping with. This is to be understood from their personal case-history. Clearing, e.g., or having an independent task, was no longer the privilege of a few women who had already been doing this for some time. Also the other women, who used not to get the opportunity, now got an assignment that was equally appreciated.

Gradually the mutual differences fade, but now we see that the adults in the houses across the street strongly disassociate themselves from the children in the institution. They do not really consider themselves or feel like handicapped people, at least not like the children in the institution. It is mostly decided upon what kind of work they will do, after considering their capabilities, their wishes, and the available jobs. Up to now all women have their

jobs within the organisation of our own institution, i.e. in maintenance and/or in the Day Centre. Although they do not receive any wages for their work, every adult disposes of a financial allowance, BF 2,000 of which can be spent monthly as pocket money. For many of them the control of this sum demands serious attendance, a first cause being the lack of insight in the value of money. Furthermore they have only very recently been allowed to dispose of it freely. But even now we see a tendency towards a more thoughtful choice, though an attended one.

3. 3. Also because of the limitation of working hours and the orientation of life towards the ordinary citizen's life (cfr. normalisation principles), there was more time for leisure.

Indeed, the increase of spare time is one of the main concerns. We have already mentioned that there used to be only little spare time, which was spent passively, watching the telly or walking about. Organizing and living their spare time was something else they had to learn. Furthermore, a change of mentality had to be achieved. Relaxation to them meant playing, and playing was for children.

Other adult forms of entertainment were introduced. Especially in the very fact of living somewhere, there were many possibilities of choosing a suitable passtime. In decorating and furnishing their living-room and bedroom, there was sufficient motivation for creative manual work and hobbyism. For others the right choice turned out to be the care of animals or plants. But active relaxation got a certain acclaim, too, as they were taught various sports and games, which although the rules were simplified, strongly resemble sports as practised by anyone. New skills, s.a. cycling and swimming were introduced as well.

A few of them joined in with some village initiatives. As they are familiar with several possibilities now, because they have learnt them from the attendants, or just because they have seen them on TV (e.g. It's a knock out!) or in corporate life (pedestrianism), they are able now to make their own choice, even to formulate suggestions. In this respect they are encouraged by their attendants in informal discussions, but also at formal meetings. Since last year "house talks" (talks among the residents of one house) and a "resident board" (board of representatives from the various living units) have been created.

Leisure was an obvious point of discussion. In this way they learn to look for suggestions themselves, and they also learn how to reckon with each other's choice.

At the beginning of the summer, e.g. we met to discuss what kind of activities could be organized. Those who could not tell or remember too well (for most of them can neither read or write) had made a list of sketches and drawings, depicting their suggestions. Sport and games really do constitute an accepted and favourite part of their spare time. Taking part in the various types of relaxation in the village—i.e. outside their own circle, does not always go smoothly. Although an important step has been made, as a few among them regularly take part in meetings of the village societies, dances e.g. remain difficult moments. Because they themselves do not know yet how to behave in certain circumstances, and also because the community is not yet spontaneous and open, some forms of entertainment remain a difficult choice. From this we can learn that in order to choose something one has also got to feel sufficiently safe to realize that choice.

3.4. It will not have escaped your notice that in all this very often a strong appeal is made to flexibility, to their capabilities of development. We have already emphasized a lot of educational moments concerning residence, work and leisure. But also an appeal was made to their being human as persons and as members of society. During the transitional period and during the intensive attendance after the removal, a special appeal was made to their being adults. By paying attention to their clothing, and emphasizing their social competence, their attention is drawn to their being adults, to their being women.

From the very beginning another important point in the attendance was to smooth their manners. Though sometimes the law of the jungle used to prevail, now they were taught to live as equal companions. The happiness and amazement about their new home at first acted as a lightning conductor in the more intense interaction. When they had found their feet again, a new phase began: namely the exploration of the others and of oneself. What is my position in this house and what position do I give to my fellow-residents?

For quite a long time subgroups kept existing, according to their origin or former status. This is now gradually changing. The following examples may illustrate how these group dynamics are connected with "choice". In one of the units, an educatress, who had been attending the residents from the very beginning, went to work with another living unit. Because of this, and because of an

272 enlargement of the team, two new educatresses took her place.

The residents lived through a period of seeming calm. Everyone showed her best side, but after some time they showed clear preference for one of the educatresses, according to her own sympathy, but also according to existing mutual relation patterns: the fact that A chose B, was a reason for C to choose D.

Another shift took place in the same unit: the head educatress left, she was succeeded by her colleague. From this moment on, she experienced that the residents came to her with the questions and problems they had gone to the previous head educatress with before.

This shows that living together ends up in making a great number of choices. A complex event, insight into which is only gradually achieved, as one gets to trust one another more.

So we see that choosing is not only affected by the attendants, but also by the inmates themselves. A good reason to be very careful in composing living units.

As for the exploration of their own personality we have already pointed out that the changed working situation and living situation prompted the women into constructing a new image of themselves. Some of them used to construct a feeling of importance and respect through their work or through managing their own room, in which way they could measure out for themselves a place among the others. This was partially abandoned. Not suddenly but gradually they had to go through this transition period. Also they were now closely attended on by people who were younger than they were and who resembled them more than the older nuns did.

All this involved a certain initial revolt against the educatresses, or against the other women who came to live with them. They had to create a new place for themselves, a new role, a new identity; and they are actually still working on it. Even though the residents have experienced the importance of attendance and though they have learnt to take part in the more intensive group interaction, some conflicts have not become less violent. But also in difficult moments they learn,—as we all do, by the way—to be more independent, and yet more sociable.

3.5. When residing, work and leisure have been evaluated, and particularly when our own attendance and the development of the residents is critically considered, we must conclude that we are confronted again and again with a particular tendency. We can notice the following evolution in the making of choices by the handicapped people themselves:

At the start there is the attendance that shows the handicapped people the opportunities of their new condition of life; afterwards an attempt is made to teach them the necessary skills to carry out their choices; and finally, the mentally handicapped person gradually achieves some independence in action, through consultation with her educatress. From all this we can conclude that the whole personality and the professional ability of the educatress plays an important part in the choices her people make. This is a second relativity in the concept of "choice" . . . Not only the social context, but also the people in their immediate surroundings impose some limitations. This is a fact that in our opinion cannot be sufficiently emphasized.

A second conclusion from the ascertained evolution is that choosing must be learnt. From the point of view of their own case-history they have to get acquainted with the new aspects of their new life style. In this didactic process we recognize again the evolution mentioned above: at first it is the attendants who occupy nearly all leading functions, but in the course of time the possibility arises that at certain moments certain functions are transferred to the residents themselves: e.g. choice of recreation, of desert, etc. . . .

4. Conclusion

We can conclude by saying that a positive development has taken place. Also the residents themselves can find sufficient arguments to give a negative answer to the question whether they would like to return to the former situation.

Of course, there are many possibilities and a few worries for us that we would like to propound to you in conclusion.

4.1. In the first place there is the question whether ten people living together day by day is the best possible solution. We could ask ourselves if the positive development they have already gone through could be continued or rounded off with a still different life style which would give them even more tranquility and opportunity to self-determination. Here we can also put forward the question as to which is the most optimal ratio as for the number of educatresses per living unit, and the influence of this ratio on the development of the residents.

4.2. There is also a lasting concern as to the influence of the attendance, for we have seen that the inspiration and commitment of the educatress is the basis of the capability of the

choice directly depends on ours. All this evokes a lot of questions: what about the attendance, training, selection etc. of the educatresses, educators, therapists . . . ?

4.3. There is also the ascertainment that choosing is subject to some relativity: limitations due to the surrounding community, a limitation in the social historical context, a limitation in the physical surrounding, a limitation in the attendance.

4.4. There is also the continuous concern to find out about their possibilities, so that we can make sure that we do not ask too much or too little of their being human. We could ask this question for instance concerning their jobs. Would they not rather have a real job? We hasten to add that in our opinion their having a job must be considered as part of their whole living and being.

4.5. We have also pointed out the age difference between educatresses and residents. This goes with another problem: how to preserve the continuity in the attendance of the residents, who will probably live in the homes for the rest of their lives, whereas the educatresses will only work there for a limited period of time. What does it mean to them always to have to let familiar people go away, to see them replaced by new (young) ones.

4.6. A home in the village is an unconscious utterance of integration, but what kind of integration is it to become?

4.7. And finally I would like to draw your attention to a last point: the ageing of our people. What does this mean to them and what are the consequences for us? These questions will demand a great deal of attention and commitment from us in the future.